þÿPerceptions of Members in Parents Association
þÿwith Disabilities of their Children s Opportunitie

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3 Perceptions of Members in Parents' Associations for Children with Disabilities of their Children's Opportunities to Play

3.1 Parents' Associations survey

The Action "LUDI. Play for children with disabilities" developed the survey about the views and needs of users in various contexts in 2016, asking members of Parents' Associations for Children with Disabilities (PACDs) their opinions and views when it comes to their children's opportunities to play. Why the questionnaires were addressed to Parents' Associations? The voices of children should be heard through representatives of associations because they have a wide knowledge on many cases and can report the playing conditions in disability, showing the influence that the political and cultural aspects have on this issue.

The Parents' Associations were contacted to easily get information from a knowledgeable user base which is directly involved in the disability needs.

In each country participating in the Action, a member responsible for the data collection on users' needs was asked to contact parents' associations of children with disabilities in order to elicit the experiences and views within their organisation, concerning the children's opportunities to play and to submit their answers in the web-survey. The national responsible was suggested to collect if possible answers from at least three associations, disregarding the type of disability. The reason for this is because the answers should provide just a snapshot from European context with valuable information about the children's experiences and needs in this field.

It was more important at this step of the Action to get knowledge about general needs of children with disabilities than to inquire about the differences between types of impairments, or about specific cases of children. The answers were reviewed and analysed by members of the Action "LUDI" Working Group 4 and subsequently compiled in the present report.

3.1.1 Participating Countries

Countries participating in the survey were Austria, Belgium, Bulgaria, Croatia, Cyprus, Denmark, Finland, France, FYR Macedonia, Germany, Greece, Hungary, Israel, Italy, Lithuania, the Netherlands, Poland, Portugal, Romania, Serbia, Spain, Sweden,

Switzerland and Turkey (N=24). Five more Action "LUDI" countries were asked to participate to the survey but they did not provide answers, during the timeframe of the present data collection, March-June 2016. Numbers of PACD participating from each country varied from 1 to 9, with an average of 3 and a total of 75. Italy and Romania were representing countries with 9 and 6 participating PACDs. Austria, Denmark and Portugal in turn, had 1 PACD per country that answered to the survey.

As a whole, the participating countries show a rather good geographic distribution, with representing countries from East, West, North and South regions of Europe, which indicate that the survey was able to collect opinions from quite different societal contexts.

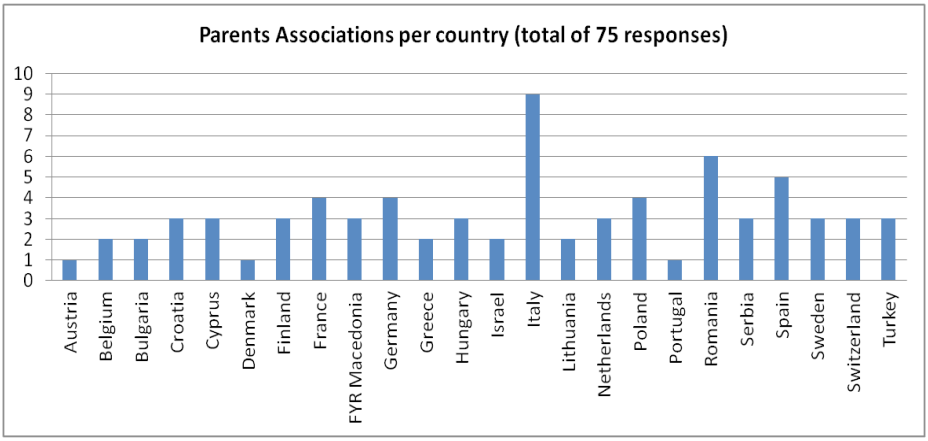

Figure 1. Number of PACDs per country (N=75) in alphabetical order

3.1.2 Types of impairment/disability represented and ages

The knowledge of the type of impairment and of the age of the children gives the opportunity to establish some considerations about these indicators.

PACDs participating in the survey were representing a wide variation of disabilities (Fig. 2) such as intellectual impairments from mild to profound (19%), autism spectrum disorders (17%), communication/language disorders (15%), multiple disabilities (14%), physical impairments from mild to severe (12%), visual impairments from partially sighted to blind (9%), hearing impairments from partially hearing impaired to deaf (8%), and other (6%). The respondents that reported the alternative "other", in addition to the offered choices or as the only answer, added as specification – e.g. Down syndrome – or other conditions and diagnoses – as developmental disorders, cerebral palsy, dyspraxia, attention deficit hyperactivity disorders, very premature infants, and developmental delay in learning and behaviour. In one case it was

reported that the children were also deprived, in addition to having disabilities. In this regard the Action "LUDI" focuses on the play of children with disabilities related to category A in the cross-national recognized sense of OECD's (Organization for Economic Cooperation and Development) Centre for Educational Research and Innovation, therefore it caters to children with disabilities or impairments viewed in medical terms as organic disorders attributable to organic pathologies[2].

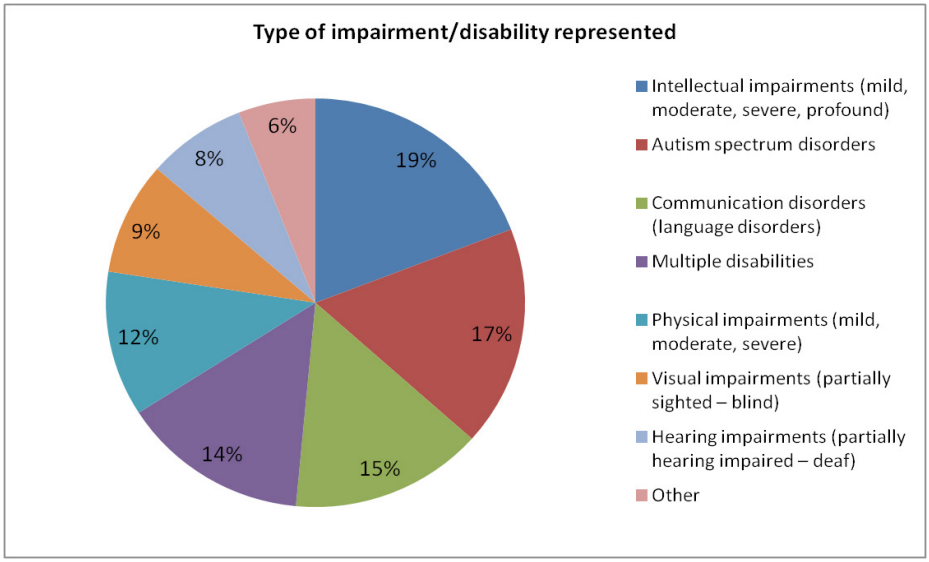

Figure 2. Types of disabilities (percentages) represented by the PACDs (N=75)

The Parents' Associations that participated to the survey represent various types of disabilities, with a rather even distribution between the types. It should be noted also that each association could report that their members included more than one type of disability.

32 Associations reported that they represented persons with disabilities of all ages, while 25 Associations are only in charge of children up to the age of 18.

2 OECD. *Students with Disabilities, Learning Difficulties and Disadvantages: Policies, Statistics and Indicators*, 2005, 2007.

3.1.3 Parents' Association members

The Associations collect members and operate at a local, regional or national level. Most of the PACDs participating in the survey have a membership of up to 500 participants. Within the countries participating in the survey, 21 PACDs had more than 500 members. All in all, the participating PACDs are estimated to represent at least 87.544 persons with disabilities, with a restrictive estimation.

Table 3. Numbers of members of PACDs

Number of members	Number of Associations
< 100	25
100 - 499	21
> 500	21
No response	8
TOTAL	75

This number is a lower bound since the estimation builds upon the consideration that the number of members reported in many cases corresponded to the number of families. When an interval was indicated by the respondent, the lower limit of the interval was considered to perform the calculation.

3.1.4 Opportunities to play according to the needs

Regarding Question 1, asking if the children with disabilities have sufficient opportunity to play according to their needs, 31% of the participating PACDs answered that children with disabilities represented in their Association do not have the same opportunities to play as the other children. 42% of the respondents answered that the children with disabilities had to some extent opportunities to play, while 15% stated that the children with disabilities that they represent have a lot of opportunities to play. Additionally, 12% of the respondents reported that it was impossible to give a general answer to this question (Figure 3). This question is aimed at understanding the perception that the Association's representatives have with respect to the needs and the value of play.

3.1.5 Parents' happiness/satisfaction with their children's play

Regarding Question 2, about the happiness or satisfaction of the parents with their children's play, a majority of the PACDs (64%) thought that the parents of the children with disabilities that they represent are not happy with their children's play. A little more than one third of the Associations thought that the parents were happy with their children's play (Figure 4).

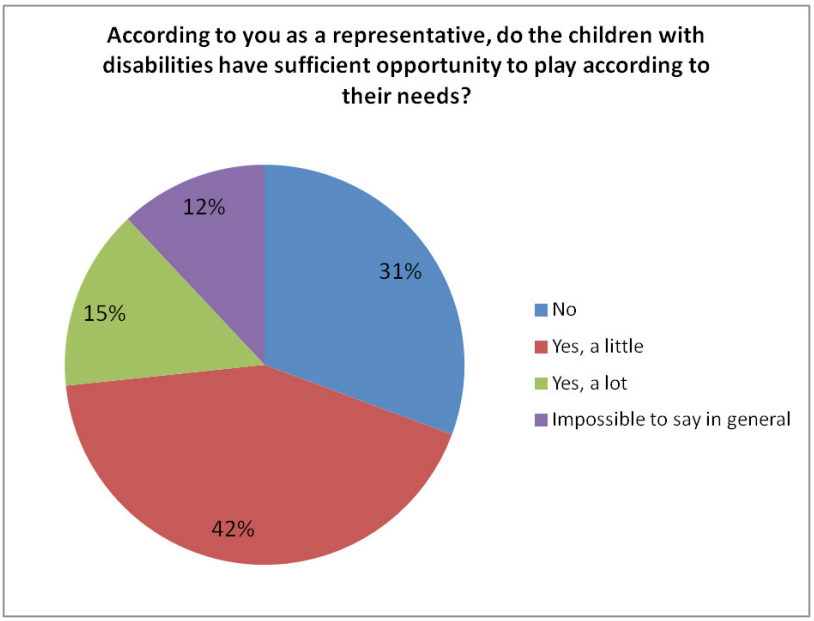

Figure 3. Opportunities to play according to the children's needs represented by PACDs (percentages).

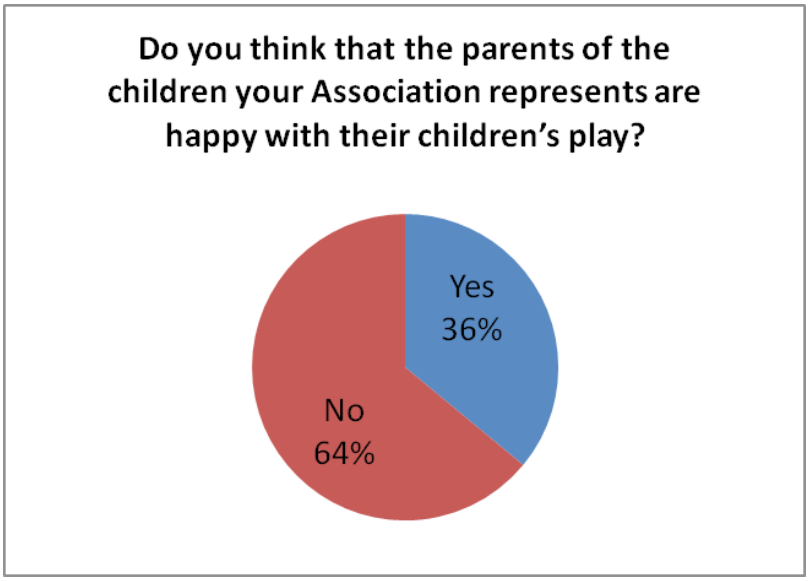

Figure 4. Parents' happiness with their children's play according to representatives of the PACDSs (percentages, N=75).

The respondents could add comments to this question. The comments are analyzed and summarized here and can thus be considered examples, in term of limitations, restrictions, as well as facilitators and barriers, to play for children with disabilities.

Among those that answered that the *parents were happy with their children's play* (36%) there were 7 comments. Some comments were linked to toys that were available and adapted: *all our children prefer music toys* and *children can play with many kind of toys, not only the ordinary ones*. In one comments *toys' library* is mentioned and another answer handles *parents' inventive* to find appropriate play material. In two comments the representatives alluded to resources available through their Association; *we have appropriate spaces, facilities and have trained staff* and *we provide them opportunities for playing*.

Facilitators of play were thus mentioned within these comments: specific toys, adapted toys, broad range of available and accessible toys to loan, parents' creativity, purposeful planning and other resources in available space, premises and educated staff.

Among those Associations that answered that the *parents were not happy with their children's play* (64%), 44 comments were gathered explaining the motives behind their opinion.

In some answers the parents' dissatisfaction with play was related to activity performance and play preferences: impairments, activity limitations and participation restrictions were viewed as restricting the play activities that a child could take part of and were also impacting a child's play preferences.

One theme related to this category is children's characteristics: in fact, 14 answers related to children's characteristics as reasons for this dissatisfaction were produced. Most of these answers concerned the restrictions that children with autism spectrum may experience in contact with others, as well as their tendency to isolate themselves. The experiences of children with physical and multiple disabilities were also mentioned in this category. Some comments are reported below.

> AS [Autism Spectrum] children tend to be alone.
> The play of ASD children is lonely, repetitive, lack of diversity and [is] mainly sensory-motor.
> [Children with] multiple disabilities cannot enjoy to normal, standardized or frequent play.

Physical barriers were mentioned too: accessibility and usability of the physical setting that may limit play.

The outdoor play environment – both natural and structured – were also cited as entailing barriers to play.

> Children have difficulties in playing in natural environments.
> Playground are not adapted for children with disabilities.

The lack of toys as well as the lack of not specifically adapted games may be considered also under this category. The need of games and toys which allow children to play independently is mentioned 10 times. Some examples are reported below.

> There are not specific games to some target groups, for example there are no fairy tales or films adapted to sign language.

> Grip toys, manipulation toys and movement games can only be applied with support. Independent creative games are not usable or usable only with assistance.

But most of the comments (22) concerned the category: "Social barriers - attitudes and behaviors". They may encompass exclusive or inclusive attitudes and behaviors by peers, teachers, professionals, parents and relatives. Four themes were identified in this area: discrimination, peer relations, parents' skills and human resources.

As to the theme discrimination, the comments included both discrimination imposed by typically developing children and by their parents, as well as discrimination issued by society at large.

> The majority of parents having handicapped children avoids the public spaces because of the discriminatory attitudes of parents with healthy children. Some specific behaviors of children with autistic disorders are making the parents with healthy children to not allow their children to play with autistic children.

> Negative attitudes of neighbors and of other children.

> The older the children, the more difficult it becomes often; exclusion at the playground, e.g. because of unusual behavior.

> There is a wide variation, depending on the experiences in educational contexts and socio-cultural context of belonging.

In 8 comments the scarce possibilities of developing peer relations and the lack of friends are considered the cause of children's limited play opportunities.

> The parents are partially happy with the children's play with toys and play with an adult. They are less happy with how the children play with other children, in particular free play. It is difficult in the after-school centers / children recreation centers with too high numbers of children. It is a source of anxiety and sadness for the parents and the family, when they realize that the children are not participating in the activities in school, preschool and after-school centers. It is something that the parents talk about as an important issue.

> Children with disabilities have not opportunity to peer play with children who have better skills and opportunity to explain how to use the toys.

In this last comment the lack of peers that can act as play role models is regarded as a barrier to play for children with disabilities; this occurrence may depend in turn on

a lack of an experienced inclusive educational environments, where children with different abilities may freely interact.

There were only 4 comments about parents and their attitudes or skills supporting their children's play. In one comment the respondent said that parents differ a lot, depending on their expectations and abilities related to children's play.

> Parents feel helpless in front of the child playing in a way unusual for them, or, [that] apparently, does not play. They experience the difficulty of not knowing how to behave and feel inadequate parents.

2 comments mentioned the lack of human resources that could make play opportunities better to children with disabilities.

> It is difficult to organize adequate spaces, needed skills and professionalism are not always available. This is why we also take care of training for both our staff, both support teachers and not least for the parents

3.1.6 The importance of play "for play's sake" for children with disabilities

Question 3, asking if play "for play's sake" is important for children with disabilities constitutes the basic assumption on which the whole Action "LUDI. Play for children with disabilities" engages.

The play is a topic widely recognized in education, in rehabilitation and in the context of the rights of children with disabilities: from research we know that children learn a lot from playing, and we know also that play has been established at international level as a right in childhood. However, the *play for play's sake* is not yet an established theoretical construct nor a cultural fact. For this reason, it is interesting to know the value that the users assign to play in itself.

Following the answers from the participating PACDs we can conclude that the dominant view is that "play for play's sake" is no less important for children with disabilities than for the other children. In this survey 72% of the respondents share this opinion (54 Associations). From the answers it's also notable that 23% of the respondents found it important with play for play's sake "whenever it is possible" (17 Associations). These answers may show that there is a common understanding around the fact that play can be hindered, either in favour of training activities, routines and care activities, or due to the lack of availability. Finally, only 5% of the respondents thought that play always should have a goal, and none considered play as not important.

The comments of those who answered that *play should have a goal* explain that play in their view should be mainly finalized to achieving educational or rehabilitative objectives.

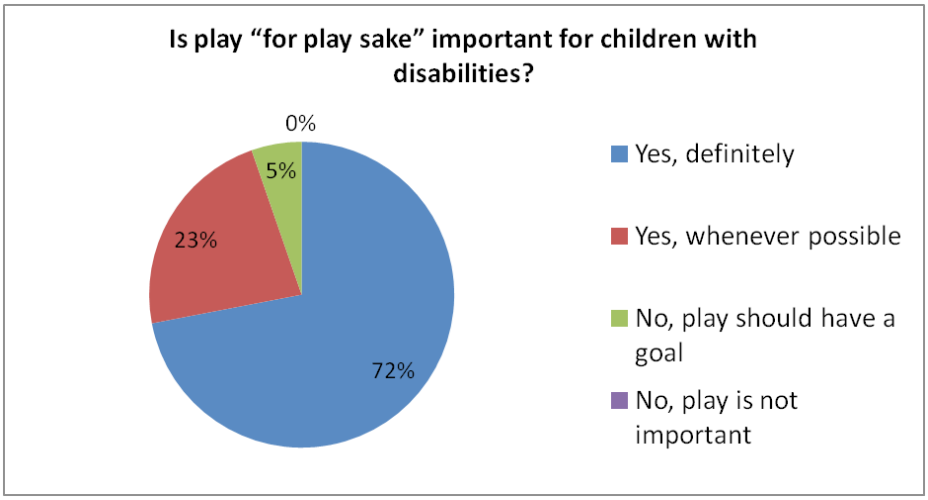

Figure 5. Importance of play for play's sake for children with disabilities represented by PACDs (percentages, N=75).

The comments of those answering *whenever possible* may indicate that play is certainly supporting children's development, and also that play is considered as oriented to learning. Some comments identify also as barriers some situations related to specific disabilities: for example, that children with autism are trained to play and thus it can be difficult to separate and distinguish their experience of learning from their experience of play; or that children with cerebral palsy may need adapted toys and environments in order to be able to participate in play.

Among the large majority of respondents that answered *yes definitely* many comments (35) were added that can be grouped around some central themes, as presented in what follows.

9 comments emphasize that play is a very important and basic activity for all children; they used expressions such as: *extremely important*, *very essential for all children*, *play is children's main activity*, *a component of a child's natural development*, *inherent to humans*, *a basic need like sleep and protection*, and as *a necessary, not optional, factor for children's growth and development*.

13 comments explain that play is related to learning in terms of specific skills (social, relational, emotional skills, basic experiences for daily life) and abilities (cooperation, creativity, communication, logical reasoning) that are practiced through it, and also in terms of more general kind: understanding life, understanding oneself and the world, making experiences of discovery and even *the only way to acquire knowledge and skills*.

Play is also viewed as a common language with peers, as a medium for communication, friendship and understanding between children, through which the children may experience a feeling of belonging to their peers' group.

Play is good for children because *they become happier as they play*, thus it makes the child feel positive emotions: while playing, they experience enjoyment, happiness, pleasure, joy, fun, and also relax, and these emotions are viewed in some comments as important for everyone.

Another reason of the importance of play is that the children as agents elaborate their experiences and express themselves with play, which, among other things, allow people in their environment to understand them and their needs. Play is also defined as a right for all the children.

Some (3) comments point out the importance of play as a tool in preventing difficulties possibly related to a disability. For instance, play can help in preventing and solving some emotional difficulties, or in supporting the development of executive functions, an area that may need intervention. The lack of play is viewed as a symptom of disability itself in another comment.

Other (5) comments involve the role that adults have in relation to children's play. Some comments state that play should be facilitated by the adults, who may adapt the play environment to the interests and the needs of the children; another comment states that the professionals can also take advantage of the pleasure that play originates in the children and use the play activities as mediators to reach other objectives. Furthermore, supervision by adults may be needed in order to avoid risks or repetitive behaviors. One comment identifies also the concern that some parents may not recognize the importance of play, thus prioritizing instead the training of motor and communicative skills in their children.

Summarizing, the largest group of representatives from the Associations considered play for play's sake essential for a wide range of reasons which can be related to socio-anthropological, psychological, developmental, and educational theories.

A widely shared belief is that play is necessary and leads to an array of positive outcomes for the child; even if play is mainly experienced as a free activity without specific objectives.

The answers from the parents' Association give a strong support to the conception of play for play's sake as very important for children with disabilities. This conception seems largely shared among the participating Associations.

3.1.7 Needs of the children in order to play (more, better)?

The Question 4 investigates the experienced play needs and their nature. The respondents were given several options and were asked to indicate the perceived level of importance.

In order to let children with disabilities play more or better 93% of the respondents answer that peers are essential (very important/important). Societal attitudes and behaviours are referred as an important or very important factor (87% of the respondents), when it comes to facilitate play. An equivalent answer (87% of the

respondents) considers important or very important to have access to a knowledgeable adult. As much as 84% of the participants in the survey regards time as a necessity, to make children be able to play. Other quite high ranked aspects, making it possible for children with disabilities to play, are: adapted or special environments (79%), policy measures/financial resources (79%), outdoor environments (77%), improved skills needed for play (72%), toys (69%), indoor environments (68%), high-tech tools/ assistive and technologies/robotic tools (59%).

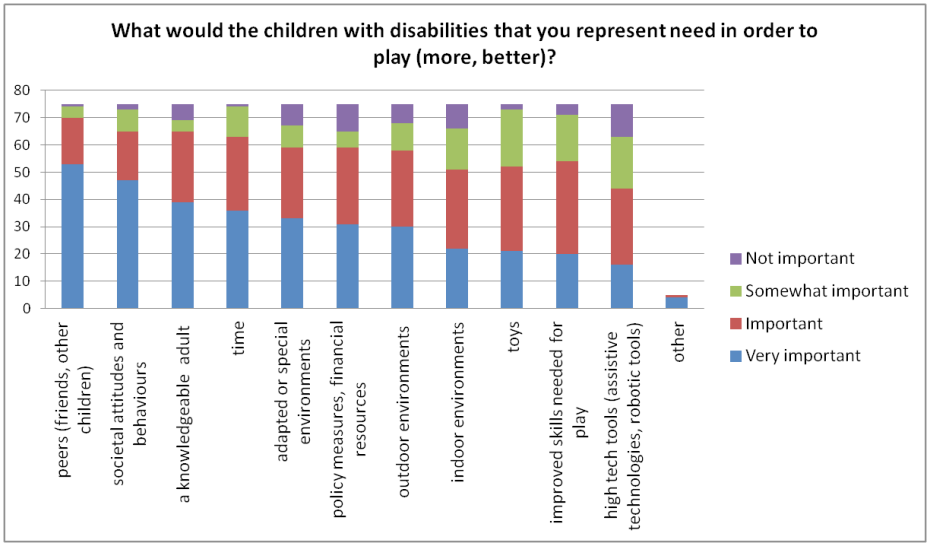

Figure 6. Needs of children with disabilities in order to play more or better, according to the representatives of PACDs (N=75).

5 respondents added some contents that they considered important or very important in order to allow the children with disabilities that they represent to play more, or better. One thing that is needed is the availability of adapted, age-appropriate toys, that are adapted to a user at an early-stage ability but that are illustrated with pictures that are age-appropriate and thus not with infantile subjects; thus a broader range of toys are needed that are suitable for users, whose developmental needs and interests follow a pattern that is not a 'mainstream' one. Another answer says that providing information to the parents about the importance of play for children with visual impairment would be very important. Research on play and ludic behaviour is also very important for another respondent. Activities and qualified people, rehabilitation services and support to the families are mentioned by two respondents and are grouped together as similar, since they both ask for qualified and supportive services to the families. Something that stands alone and is needed according to one respondent is the motivation to play as a prerequisite to engage in play.

3.1.8 Play environments and play partners

The survey gave the opportunity to get a picture about the contexts and the situations where children with disabilities usually play as well as about their play companions. In fact, Question 5 investigates which are the most used play contexts of children with disabilities (formal/non-formal, outdoors/indoors) and who are their playmates (children, adults, family members, others).

Current indoor environments are: homes and other houses, schools, culture and rehabilitation centres as well as leisure centres for children. Current outdoor environments are: playgrounds, parks and natural environments, gardens/courtyards/streets and outdoor sport centres. Looking at whom children with disabilities are most frequently used to play to (in combination with where) it seems to be more common playing with parents or family members at home than with peers or friends in schools. The survey shows also that children with disabilities are more often used to play alone, even in presence of peers, than to play with peers or friends in outdoor environments, such as playgrounds, parks and natural environments and gardens/courtyards/streets. In outdoor sport centres instead, children in this survey seem to play a little bit more with other children and youth, rather than alone.

Table 4. Environments and playmates for the play activities of children with disabilities according to the PACDs.

		WITH WHOM				
	WHERE	**alone**	**alone, in presence of peers**	**peers (friends, siblings, ...)**	**parents, family members**	**other adults**
indoor environments	home, other houses	30	12	27	49	15
	Schools	14	28	39	2	22
	culture and leisure centres for children	5	16	24	14	18
	rehabilitation centres	15	16	18	5	28
	Other	0	1	1	0	1
outdoor environments	gardens, courtyards, streets ...	21	23	26	27	8
	Playgrounds	18	26	27	27	13
	parks and natural environments	17	21	26	37	15
	outdoor sport centres	12	11	28	18	22
	Other	2	2	2	2	2

3.1.9 Changes in the play of children with disabilities

The Question 6 investigates whether according to the perceptions of parents' Associations there have been any developments about play of children with disabilities and in which fields (technologies, policies, educational sciences and rehabilitation, but also cultural attitudes and behaviors).

According to the respondents to this study, there have been more or less improvements, when it comes to play for children with disabilities within areas such as attitudes and behaviours among educators (N=42), adults (N=44), society in general (N=47) and peers (N=46). Even more noticeable improvements were reported in areas such as high tech tools (N=61) and outdoor environments (N=53). In high-tech tools was reported the higher numbers of very large changes (N=13) by the respondents. Toys were also perceived as having improved much or very much by a relatively large number of respondents. In the other topics there were rather small numbers of respondents that were reporting very large or large improvements.

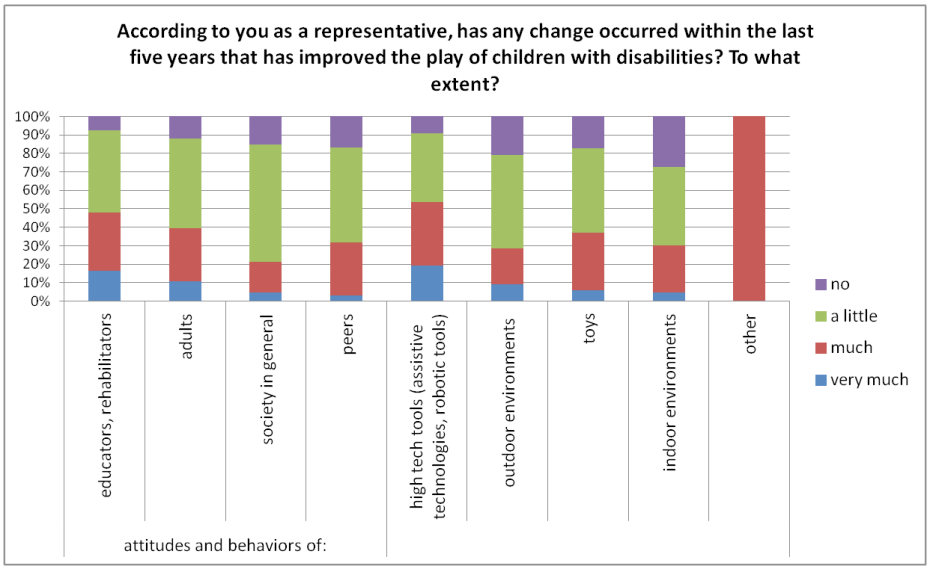

Figure 7. Changes occurred in play for children with disabilities in the last five years, according to the PACDs (percentages).